



A Time for Action: Guidelines and Goals

ACAMH Conference
September 2019

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Recommendations from SIGN 156 in making the Diagnosis

(Published January 2019)

*First UK guideline for children & young people affected by
pre-natal alcohol exposure*

To provide clinicians with a standardised
approach to assessment and diagnosis

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What is SIGN?

- Scottish Intercollegiate Guidelines Network
- Part of Health Improvement Scotland (HIS)
- Produce nationally recognised , evidence based documents to support best practice in health and improve patient outcomes

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The SIGN process

A SIGN group considered all the relevant **international research evidence over the past 10 years** in relation to the diagnosis of children affected by **prenatal alcohol exposure**. Review groups are **multidisciplinary** and include appropriate **parent and child representation**.

Key questions:

- Best available way to record accurate alcohol histories
- Current, most reliable way to assess for the possibility of Fetal Alcohol Spectrum Disorder
- Post-diagnosis outcomes

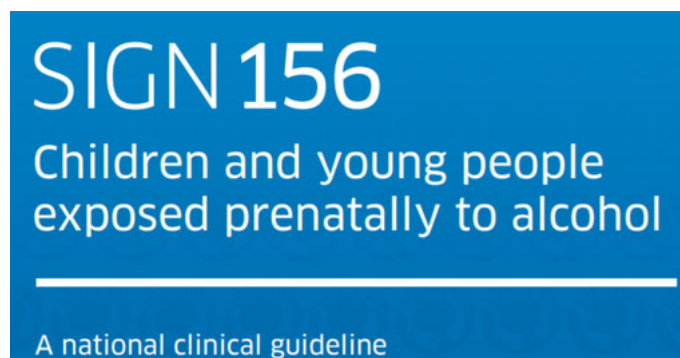
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What did we learn from the process?

- There is a need in Scotland to identify this group of children and young people affected prenatally by alcohol exposure (PAE).
- It identifies for us a 'how to do it' best practice guide (based on the Canadian Model).
- The importance of multi-agency work.
- The benefits possible for this patient group - especially educationally, and in relation to prevention of secondary mental health problems.
- There is much scope for research in this area of work.

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See details at:
www.sign.ac.uk



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Benefits of the SIGN guideline

- Standardised approach for clinicians.
- Terminology used now mirrors Canadian Guidelines, and those used in Australia and New Zealand:
 - *FASD with sentinel facial features*
 - *FASD without sentinel facial features*
 - *At risk from neurodevelopmental delay related to prenatal alcohol exposure*
- This will allow consistency in information gathering as data collection will be key to evidencing improved outcomes .

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Essentials for making the diagnosis

- History of Prenatal Alcohol Exposure (PNAE/PAE)
- Neurodevelopmental assessment indicating impairment >2 SD or high variation in scores across 3 of 10 neurological areas of assessment/ 'domains' (one of which may be brain anatomy)
- Measurement of Facial (Sentinel) features:
 - ❖ Lip philtrum and eye measurements

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SIGN Guideline:**Medical assessment 3.2, Recommendation 3.2.1**

- The diagnostic process should include a family, social and medical history as well as complete physical examination. It should adhere to a neurodevelopmental approach.
- **History**
 - Broad assessment
 - Antenatal, birth and developmental history
 - Robust alcohol history
 - Past medical history
 - Family history
 - Social history
- **Examination**
 - Growth parameters
 - Head circumference
 - Microcephaly <2nd centile
 - Facial Features
 - General physical examination
- **Exclude other causes**
 - Genetics

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SIGN Guideline:**Sentinel Facial Features, Recommendation 3.3**

- Measure:
 - Palpebral Fissure length
 - Size
 - Upper lip
 - Thinness
 - Philtrum
 - Smoothness
 - (can also utilise photographic Facial Recognition Software)

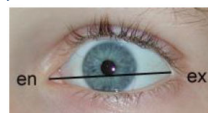


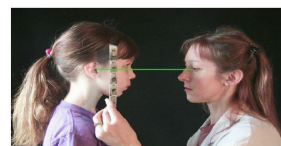
Figure 2A. Palpebral Fissure Length (PFL). Distance from endocanthion to exocanthion.



Figure 2B. PFL measured with a small ruler while patient looks up to fully expose exocanthion.



Figure 4. It is important that the patient have a relaxed facial expression (no smile). A smile can alter lip thinness and philtrum smoothness. This is the same person with and without a smile. Note that without the smile, the lip and philtrum would both receive a correct Likert rank of # 1 on the Caucasian Lip-Philtrum Guide 1. With a smile, the lip and philtrum would both receive an *incorrect* Likert rank of # 4.



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Only 10% of those with FASD will have facial features

This means that most children affected by exposure to alcohol prenatally will not look different...



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FASD requires multidisciplinary assessment

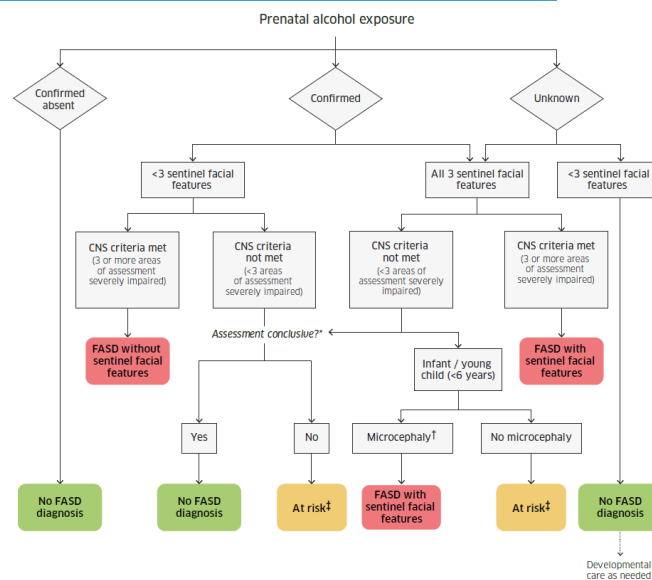
FASD is a whole body diagnosis, affecting the brain, central nervous system and physical development.
Features include:

- A 'patchy' cognitive profile with a 'disorganised' brain.
- 3 or more affected brain areas of assessment/domains indicating CNS impairment. (<2 SD)
- High variability from individual to individual.



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SIGN Diagnostic algorithm for FASD



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Particular relevance for CAMHS colleagues...

- Your help is needed to **identify children who require diagnostic assessment**.
- Consider children who may have been **missed** and/or in the **‘wrong’ diagnostic group** (particularly ADHD, possibly ASD).
- Help with the **multiagency assessment** of areas of brain function.
- Changing the climate in educational environments to see these children as having sustained **significant brain damage** that requires **appropriate support**.
- Add to the **body of research** that will advise on their future success.

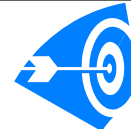
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Making a diagnosis will be dependent on...

- **Referrals** of children being made **appropriately**.
- **Heightened awareness of clinicians**, thinking about FASD as a possibility.
- **Normalising alcohol consumption recording**.
- Gaining **parental and child trust** that making the diagnosis will **make a difference**.
- Emphasising the potential **educational gains**, and the long term **preventative impact** for the child of having a diagnosis.

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Goals of the guideline

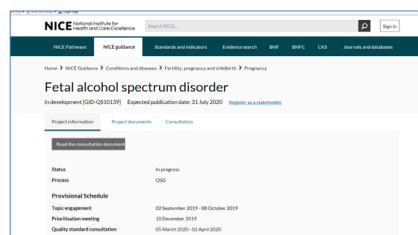


- Increased **public and clinician awareness** of effects of alcohol prenatally.
- **Better and earlier diagnosis** and **recording** of those diagnosed with FASD.
- **Better support** to children and their families.
- **Amelioration of secondary difficulties**, particularly mental health issues.
- Recognition of the need for **long-term support** for affected individuals.

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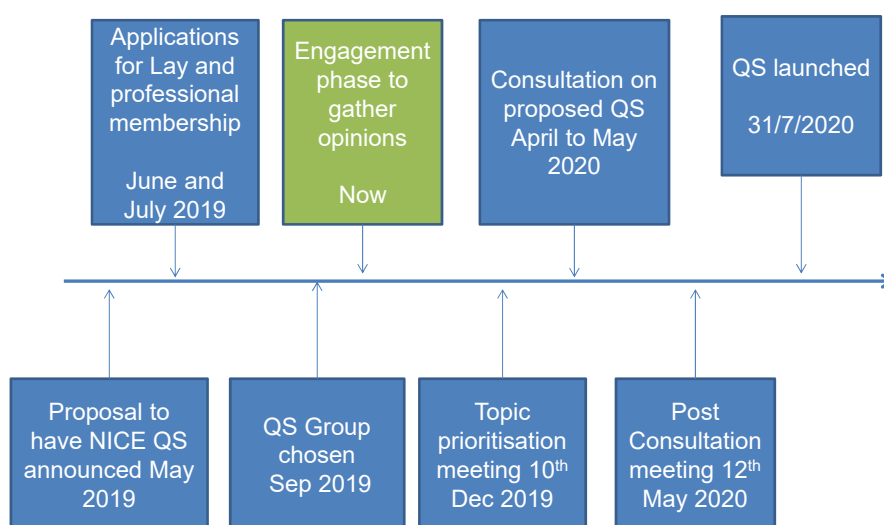
NICE Quality Standards

- Adopted the SIGN guideline - lock stock, and barrel.
- Will not change these, but can use all the recommendations, and others from existing guidance, to develop Quality Standards: cannot add more.
- 5 (and only 5) QS can be developed in all areas.
- CCG are, however, required to take note and audit against these.
- There will need to be development of separate English guidance further down the line as the Scottish health system does not necessarily immediately translate to English.



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NICE Quality Standards: Timeline



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